

Challenging representations of dementia in contemporary Western fiction film

From epistemic injustice to social participation

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To do criticism is to make harder those
acts which are now too easy.

FOUCAULT (1982: 33)

Fiction film is one of the most influential vehicles for the popularization of dementia. It is likely to have a particular influence on the way dementia is constructed by society at large, not least due to its consumption in the guise of entertainment. In this paper, we will argue that such popularization is rarely innocent or unproblematic. Representations of people with dementia in film tend to draw heavily on familiar tropes such as global memory loss, violence and aggression, extreme dependency on heroic carers, catastrophic prognosis, and early death. Audiences may therefore uncritically absorb discourses which reinforce negative stereotypes and perpetuate the biomedical orthodoxy that everything a person with dementia says or does is ‘a symptom of the disease.’

Following Basting’s (2009) view that at present, much of the cultural production around dementia reinforces rather than resists stigmatization, in this chapter, we problematize fictional representations of people with dementia in Western popular film. We do so from the perspective of critical realism. That is to say, we take the view that dementia is an ontological reality – “a recognizable, age-related syndrome characterized by disturbances

of memory (particularly short-term memory), generalized confusion (particularly in time and space), and problems with language that may be either expressive (for example word-finding problems) or receptive (difficulty in understanding others' speech)" (Capstick and Clegg 2013: 240). Dementia can, in this view, therefore be represented accurately or inaccurately, and whilst certainly subject to social construction, is not reducible to social construction alone. As Maxwell puts it:

Critical realists [...] retain an ontological realism (there is a real world that exists independently of our perceptions, theories, and constructions) while accepting a form of epistemological constructivism and relativism (our understanding of this world is inevitably a construction from our own perspectives and standpoint). (2012: 5)

The first part of the chapter draws on Fricker's (2007; 2008) concept of epistemic injustice to explore the ways in which people with dementia are currently spoken for, and about, in film aimed at a mass audience. It is important to stress that we are not so much concerned with the aesthetics of these representations as their ethics: the question of whether they *do justice* to the broader constituency of men and women living with dementia. Because the theme of this volume is 'popularizing dementia,' we focus mainly on made-for-box-office cinema, UK and US TV drama, and soap. We have, however, made reference at points to arthouse or independent film.

A certain amount of artistic license is unavoidable in film made for purposes of entertainment. Recent years have, however, seen a growth in concepts such as 'cinemeducation' and 'edutainment;' that is, the use of mainstream fiction film in the education of health and social care practitioners. Some advocates of these approaches appear to take little account of the potential for film to mislead or reinforce existing prejudice. In the second part of the chapter, we therefore apply basic principles of film and representation theory to the films recommended by cinemeducators such as Alexander et al. (2005) for teaching about dementia. Here we argue that, since there are numerous different conceptual tools for 'reading' film, student practitioners do not merely need to be shown films in order to enhance their understanding of the conditions represented in them, but also need to learn to apply theory in order to explore how film might work to construct and perpetuate particular ways of seeing dementia.

In the final section, we counterpose some examples from our own participatory filmmaking study, *Bay Tree Voices*. This project was carried out in a day care environment with people with dementia, and consists of a se-

ries of ‘naturalistic encounters’ (Capstick and Chatwin 2012). *Bay Tree Voices* draws on principles of participatory video, an approach in which people whose voices are socially marginalized or unheard become active participants and have control over the outcomes (Milne et al. 2012). It attempts to introduce into the film-making process the mutuality and rapport which Chatwin et al. (2007) identify as vital in healthcare encounters. We do not claim that these films present the truth about dementia, by contrast with the fictional sources discussed. People with dementia are far too diverse and varied a population for this ever to be possible. We suggest, however, that in keeping with Fricker’s thesis they go some way toward restoring epistemic justice.

EPISTEMIC INJUSTICE

Fricker (2007) coins the term ‘epistemic injustice’ to draw attention to the ease with which particular social groups can be deprived of their status as ‘knowers.’ According to her, epistemic injustice may manifest itself in two forms: hermeneutical injustice and testimonial injustice. Hermeneutical injustice is the failure of interpretation by a hearer or audience member due to a deficient interpretative repertoire from which the authentic voice of the speaker (the person with dementia in this case) is already absent. This results in a “gap in collective understanding [...] owing to the relative powerlessness of the social group to which the subject belongs” (Fricker 2008: 69).

Testimonial injustice is the consequent tendency for the misinformed hearer to infer that members of the disadvantaged group in question are, by definition, unreliable testators. As Fricker points out, such injustices are most apparent at certain ‘hotspots’ in social life where it is in the interests of the powerful to perpetuate the existing misinterpretation. It is clear that society’s current response to people with dementia is one such hotspot. Indeed, Fricker notes that

epistemic wrong bears a social meaning to the effect that the subject is less than fully human. [...] Such a dehumanizing meaning, *especially if it is expressed before others*, may make for a profound humiliation [...] [I]n those cases of testimonial injustice where the driving prejudicial stereotype explicitly involves *the idea that the social type in question is humanly lesser* [...] the dimension of degradation [...] is a literal part of the core epistemic insult. (2007: 44 [emphasis added])

In the case of fiction film, of course, the whole intention is to ‘express before others.’ Representations of dementia as the loss of human status, or liv-

ing death, feed all too easily into real-world public debates about the ‘burden of care,’ the social cost of improving services, and – particularly insidiously – about euthanasia. Johnstone found, for example, that metaphors used in media sources, such as the “epidemic metaphor” of dementia as contagious disease and the “military metaphor” of dementia as an alien invader, “influence the way people think and behave about the disease [sic] and its treatment options – including medically assisted death” (2011: 390).

Epistemic injustice and dementia

While the concept of epistemic injustice has been applied to structural prejudices related to gender, disability, ethnicity, and sexual orientation, it has not previously been applied to dementia as a locus of injustice. We argue here, however, that dementia serves as a paradigm example of Fricker’s (2007) thesis, in that people with a diagnosis of dementia are frequently presumed to be unreliable narrators, unable to give a meaningful account of themselves or their lived experience. Fricker’s work has clear ethical and theoretical resonance with Kitwood’s (1997) seminal deconstruction of the medical model of dementia and particularly his typology of common personal detractions against people with dementia. Kitwood argues that personal detractions (or ‘insults’) such as invalidation, disempowerment, ignoring, and disparagement can exacerbate the experience of dementia and contribute to a decline in ill-being that is relatively independent of neuropathology (ibid.: 46). Baldwin’s (2008) work on the narrative dispossession of people with dementia also has features in common with Fricker’s concept of testimonial injustice; the stories of individual people with dementia are disbelieved and discounted because they are judged incompetent by virtue of their diagnosis.

Traditionally, hermeneutical injustice towards people with dementia has been evident in many standard texts on dementia. Pitt asserts, for example, that in dementia, “sometimes it seems as if the true self dies long before the body’s death, and in the intervening years a smudged caricature disintegrates noisily and without dignity into chaos” (1982: 39). Evidently this is not a way of talking about people with dementia in which they are expected to participate or have any right to self-determination. In recent years, much work has been undertaken in the fields of dementia theory, practice, and education to challenge this form of objectifying language and imagery (cf. George 2010). Mainstream audio-visual media still, however, regularly

perpetuate such views. In strikingly similar imagery to Pitt's, for example, an episode from the 2005 UK TV drama series *Afterlife* (ITV, 24 September 2005) could claim on behalf of a character with dementia, "It's Alzheimer's; it's worse than death. The brain dies and the body carries on without it." This is an image of the person with dementia as less than human. Indeed, Behuniak (2011) points out that one of the more prevalent cultural metaphors for dementia – that of the living death or 'death that leaves the body behind' – casts people with dementia in the role of zombies. This is a particularly insidious form of mind-body dualism which not only perpetuates negative stereotypes but also fails to engage with evidence of capacities that remain intact in dementia, such as emotional, long-term, and procedural memory.

Hermeneutical injustice of the kind perpetrated in *Afterlife* results in the formation of homogenizing assumptions about people with dementia collectively; that they are, for example, mindless, insensate, and incapable of meaningful communication. This, in turn, impacts on assumptions about the capacities of individual people with dementia and leads to the second category of epistemic injustice Fricker (2007) identifies: testimonial injustice. The utterance of any individual person with a diagnosis of dementia is likely to be subjected to suspicion, discounted, or disbelieved. A particularly pernicious aspect of testimonial injustice, according to Fricker, is that instances of coherent and reliable narrative on the part of a member of a disparaged group are dismissed as 'atypical' of the group as a whole.

Brown and Clegg (2007) note, for example, that staff often disbelieved accurate claims made by care home residents with dementia about their former lives. We have also experienced epistemic injustice in the academic review of work we have carried out with participants with dementia (Ludwin and Capstick [unpublished]). Here, the reviewer's comments dismissed the accurate socio-historical recall of two people we worked with – Henry and Florence – as untypical of 'variation in the category.' The reviewer implies that the intact long-term memories of Henry and Florence are the exception rather than the rule for the 'category' of people with dementia generally. It is, however, well-established that in dementia, memory for emotionally charged events in childhood and early adulthood often remains strong, even when short-term memory is seriously compromised (cf. Leyhe et al. 2009). The reviewer's comments are therefore an example of testimo-

nial injustice against Henry and Florence personally and hermeneutical injustice against people with dementia generally.

Problematizing representations of people with dementia in mainstream film

In the context of film specifically, hermeneutical injustice can be considered part of what is sometimes described as the pro-filmic event, or 'repertoire of elements' from which the film is composed (Monaco 2001). Here the concept of the trope is a useful one, referring to the key messages, storylines, or genre-specific devices upon which a film turns. These tropes must be quickly recognizable by an audience and, as a result, mainstream film is particularly prone to stereotyping entire social groups on the basis of one or two easily recognizable characteristics. Fricker describes this form of negative stereotyping as "a widely held disparaging association between a social group and one or more attributes" (2007: 35). Whilst little critical analysis of the portrayal of dementia in visual media has taken place until recently, the representation of people with mental health problems has been problematized for many years. In films touching on mental health issues generally, stereotypes such as the crazed killer, the madman-genius, or the reclusive deviant are frequent, in spite of the fact that they do not accurately represent the vast majority of people who experience mental health difficulties (Helsby 2005). As Cassey (2005) notes, this is often because the representation of mental illness in film is angled to suit the needs of the plot and producers (i.e., the market) and melodramatic, sensationalist, or emotionally manipulative representations are more profitable than those that strive for more 'authenticity.'

Research by Hulko (2009) has shown that negative views of dementia on the part of people with a diagnosis are by no means as frequent as has been generally assumed. Such undramatic findings are, however, unlikely to provide a box office draw, or high TV audience ratings. Substitution of inauthentic 'stock characters' and perpetuation of media stereotypes therefore remain frequent devices. To give one small example, in *Rise of the Planet of the Apes* (Wyatt 2011), the onset of Alzheimer's disease for the character played by John Lithgow is signaled by his loss of ability to play the piano. Piano playing involves procedural memory, however, and this – together with memory for music generally – is far less prone to damage in dementia than short-term memory (cf. Cuddy and Duffin 2005). We cannot,

of course, claim that no person with dementia would ever lose the ability to play the piano, but the problem with such representations is that audiences are prone to generalize from them and infer that dementia inevitably involves the loss of creative skills and enjoyment of life, when this need not be the case.

We suggest then that all mainstream films need to be approached carefully, using what Ricœur (1970) terms a hermeneutics of suspicion; that is, an interpretative approach which assumes that the surface meaning of a text is an attempt to conceal underlying political interests that are served by that text. The purpose of interpretation is, in Ricœur's view, to strip away these superficial concealments in order to unmask the interests behind them. Similarly, Cassey (2005) asks us to consider the question: Who benefits from this particular representation?

Film and the public imaginary

The imaginary is a term initially adopted by Freud (1888) to describe the way in which physical manifestations of neurosis did not follow the normal rules of anatomy. The imagined body, this is to say, conforms to popular understandings of how its parts are linked together rather than to anatomical fact. Later sources have drawn on this concept to highlight how human subjects must try to make sense of external reality by means of a stream of fragmented and momentary sensory impressions, of which film is a striking example. Lebeau (2001: 54) draws attention to Metz's concept of film as a "technique of the imaginary" (1982), noting that Metz is not merely emphasizing the fact that the content of fiction film is an invention. Metz also points to the increased likelihood – by comparison with other fictional forms, such as novels – that film will be believed, precisely because it involves moving images and therefore a heightened sense of reality. In examples such as the one discussed below, the apparently benign social realism of a TV drama makes its acceptance as a faithful representation of diagnosis, assessment, and prognosis in dementia more likely.

The UK television series *Frankie* (BBC, 2013) is a 6-part drama series about a community nurse. The first episode focuses on Walter Thomas, a male character in his 80s who is living alone in the community following his wife's recent death. Walter has diabetes, and in the course of administering his insulin, Frankie, the eponymous community nurse, notices apparent signs of the onset of dementia. Despite the known association between

diabetes and secondary dementia, there is no mention of differential diagnosis during this episode, or indeed of a diagnostic process of any kind. Treatable causes of Walter's confusion (such as an infection) are not considered. When he reacts to Frankie as though she were an intruder, this is not opened up to interpretation in the social context of crime against older people or media-fuelled fear of such crime. Instead, it is presented as one of a sequence of aberrant behaviors, all of which are treated as symptomatic of neurodegenerative disease.

Individually trivial mistakes on Walter's part (for example setting off the fire alarm, not knowing how to operate the oven, and eating pie for breakfast) are treated as though they are part of the dementia syndrome. These behaviors are pathologized in Walter's case in a way that would not be possible with any other social group. Note also that genre is important in the way we are cued to read film; a 20-year old character who ate unorthodox things for breakfast and was technologically inept would almost certainly appear in a situation comedy. This episode, however, positions Walter as needy and helpless, without retained skills or knowledge. Loneliness, grief, or mere ineptitude in the use of household equipment are not considered as causal or contributory factors in his predicament. By the end of the episode, the situation has deteriorated to such a point that Walter is taken away, protesting, to an institution.

Here, a process that would, in real life, be likely to unfold over a period of several years is squeezed into a few days in the TV storyline and less than an hour of actual viewing time. The likely impression on the audience of the narrative order of events in dramas such as *Frankie* is that people with dementia are subject to rapid and disastrous decline and will quickly need to be institutionalized for their own and others' safety. In TV soaps, where events generally unfold in real-world chronological order, it is also noticeable that characters with dementia frequently meet a premature end from other causes. This avoids the loss of dramatic impact that would result if dementia followed its usual gradual progression over several years from diagnosis to death. So, for example, Mike Baldwin, a character in the long-running UK soap *Coronation Street*, whose dementia-related storyline generated significant media and public interest in 2005-2006, died of a heart attack just six months after his on-screen diagnosis, at the age of 63. More recently, another *Coronation Street* character, Lesley Kershaw, whose dementia was of even earlier onset died from accidental electrocution seven

months after her storyline was introduced in October 2011. This repeated combination of early-onset, rapid decline, and premature death in characters in a popular soap is likely to have a profound influence on the viewing audience. It suggests, for example, that dementia is a condition that people quickly die from rather than live with and that their prognosis is very poor. To date, there has been a dearth of characters with dementia in TV soaps who continue to appear over a realistic timescale, have storylines unrelated to their diagnosis, or contribute positively to their family and community.

Outlaws, bad cops and good cops: Crime drama and dementia

In the genres of crime drama and psychological thriller, representations of men with dementia are typically taken out of the domestic sphere and situated in contexts of illegality and corruption which carry veiled implications of what we might call ‘retributory pathology.’ TV drama series such as the UK *The Fear* (Channel 4, 2012) and US *Boss* (Starz, 2011) suggest that dementia may be a punishment for a criminal or morally unscrupulous past. In each of them, a powerful and abusive male character is ultimately brought down, not by former adversaries or people he has wronged, but by the ravages of rapidly progressing brain disease. Richard Cottan who wrote *The Fear* acknowledges that “for dramatic purposes,” in order for central character gang boss Richie Beckett’s dementia to become obvious to the audience within four episodes, he researched Alzheimer’s “with a vascular component [which] adds rapid degeneration to the disease’s other problems” (Vine, 2012). Whilst progression in vascular dementia tends to be stepwise rather than gradual, the suggested research does not appear to have been particularly thorough, since vascular dementia is no more likely than Alzheimer-type dementia to lead to the kind of catastrophic decline represented in *The Fear*. Here, we are given the impression of a disease entity which strikes like a punitive thunderbolt rather than the gradual onset of a cognitive problem which might be experienced by anyone through no fault of his or her own.

In the US crime thriller *Boss*, central character Tom Kane is the morally and politically corrupt mayor of Chicago (“I am a bad man, and I’ve done bad things”). Kane goes to extreme lengths to conceal his diagnosis of Lewy-body dementia. His attempts to repudiate suggestions that he has visited a neurologist imply that cognitive disability is shameful. At the same time, the viewer is made complicit in witnessing the symptoms Kane hides

from the outside world, including uncontrollable shaking and incontinence, which he can only keep under control with high doses of medication. Here, neurological disease is presented as a greater barrier to holding high public office than naked self-interest.

By contrast, the Scandinavian noir series *Wallander*, based on the novels of Henning Mankell, takes the more nuanced approach typical of this genre. The sub-plot relating to detective Kurt Wallander's dementia unfolds gradually, his lapses of memory and oversights easily attributable to other reasons for several episodes. Wallander solves his final case in spite of his diagnosis, and the series ends with his retirement party, on a note, if not of hope, of qualified acceptance. Similarly, Swinnen (2012) notes that in the Swedish film *Wellkåmm to Verona*, the main character, a man with dementia, maintains a unique identity and varied social roles including those of skilled seducer, convincing actor, and persistent lover.

THE ROLE OF FEATURE FILM IN DEMENTIA EDUCATION: DANGEROUS REPRESENTATIONS

So far, we have been concerned with the general societal impact of epistemic injustice in filmic representation of people with dementia. As educators as well as researchers, we are, however, particularly concerned with the use of film in curricula for health and social care practitioners. There is a widespread perception that arts-based teaching is invariably beneficial in practitioner education and that introducing film, literary fiction, and other arts media into the curricula followed by health and social care practitioners will have a humanizing effect (cf. Smith et al. 2006). Downey et al., for example, suggest that “[f]ilms, used as case studies, can deepen a student’s engagement with the subject matter and characters, permitting the student to empathize, identify, and develop feelings of closeness, respect, affection, revulsion, fear, [and] anger” (2003: 403).

Whilst enthusiasm for arts-based education has led to the opening up of valuable fields of enquiry such as medical humanities and narrative healthcare, the potential for art to deceive or misrepresent also needs to be borne in mind. We find disturbing, for example, Logan’s suggestion that fictional representations of ‘female psychopathy’ (including *Dangerous Liaisons*) can be used to improve rates of diagnosis for this condition in real life because they will enable practitioners to “understand the phenomenology of psychopathy in this group” (2011: 18). This claim is based on the as-

sumption that the fictional representations in question are accurate and authentic. This is a dangerous territory for medical humanities since it is almost certain that the characters and their actions will have been created for dramatic effect and to suit the requirements of a plot. They cannot be treated, in any sense, as clinical case studies.

Alexander et al. (2006), in *Cinemeducation: A Comprehensive Guide to Using Film in Medical Education*, are among the main proponents in recent years of the use of mainstream feature film in practitioner education. Their basic thesis is that film can make education more entertaining and bring medical conditions to life. "Movies are perfect for capturing learners' attention. [...] Using the material that can be found in this book, we will all have a much easier and more successful time" (ibid.: xiii), a clinical professor writes in the foreword. For teaching dementia specifically, the authors recommend that the feature film *Iris* (Eyre 2001) be used to facilitate medical students' understanding of "the importance of maintaining a routine and schedule for a patient with Alzheimer's disease" and "the impact of caregiver strain" (Alexander et al. 2005: 64). Here, it is implied that the discussion of such questions in the context of film viewing will provide facts about living with the condition in question.

Morris (2010) also recommends using the film *Iris* to teach about dementia, alongside two more recent films, *The Notebook* (Cassavetes 2004) and *Away from her* (Polley 2006). He acknowledges that viewers may have difficulty in distinguishing between reality and fiction and that many films carry "distorting and stigmatising" (Morris 2010: 146) portrayals. By comparison with Alexander et al. (2005), Morris' argument in favor of using film is orientated more toward fostering empathy with the fictional characters than to deducing facts from the storyline. At the same time, however, he also puts significant emphasis on such properties of film as its being "attractive and engaging" (ibid.: 143), "enticing" (147), and involving "charismatic and appealing stars" (149). This again emphasizes film-watching as hedonistic entertainment rather than subject matter for the development of critical thinking skills. In the next section, we will therefore first look in more detail at some of the different theoretical paradigms from which feature films on dementia might be viewed as a mode of representation.

Theories of representation: From mimesis to deconstruction

Helsby (2005) points out that representation theory has, over the years, passed through three main phases (see table 1). In the first phase, *reflective* theory suggested that art merely mirrors back what already exists, reflecting a positivistic world view. Somewhat later, *intentionalist* theory suggested that it was the message the author meant to convey that should shape the analysis of the work. Finally and most recently, *constructionist* theory focuses on the discursive aspects of the work in producing meaning and in controlling as well as responding to the beliefs that are dominant in society (i.e., a critical, postmodernist or deconstructionist perspective).

The argument in favor of cinemeducation depends upon uncritical acceptance of the ‘art as mimesis’ reflective theory and authorial intentionalist theory. Whilst Alexander et al. (2005) suggest that fiction film is a source of diagnostic ‘facts,’ for example, Morris (2010) focuses more on the film’s *intention* to create in the viewer certain effects, such as empathy and compassion. As Helsby (2005) points out, however, most recent media analysis within the field of representation theory recognizes that films both reflect and constitute social realities. Matters are thus much more complex than the proponents of cinemeducation suggest. A recent text on film theory (Lapsley and Westlake 2013), for example, traces the history of such theory through several paradigmatic stages, from early formalist, semiotic, and psychoanalytic approaches to the more recent postmodernist and deconstructionist standpoints, each of which would offer radically different readings of the same film.

Table 1: Theoretical paradigms and the view of dementia in film

Paradigm	Nature of film	Dementia view	Aim
Positivist	Mimetic; 1:1 view of reality	Progressive brain disease	Provide facts
Interpretivist	‘Life through a lens’; one of a number of ways of seeing things	Multifactorial causation; social disability	Develop empathy and social support
Postmodernist/Deconstructionist/Critical theory	Reflects and constitutes hegemonic understandings	Socially constructed	Deconstruct orthodox, taken-for granted representations

A recent article by Wearing (2013), *Dementia and the Biopolitics of the Biopic: From Iris to the Iron Lady*, serves well to contrast the positions taken by Alexander (2005) and Morris (2010) with a more deconstructionist approach. Here, Wearing develops an analysis of the gendered nature of the two films in question, both of which are biopics about well-known women who ended their lives with dementia. Commenting on what their deeper structures tell us about society's views on women, aging, and power, Wearing notes that the role dementia plays in these films is "an indication of how the condition is imagined, understood and negotiated in the public sphere" (2013: 316). Wearing's deconstructionist critique is explicitly *about* the cultural politics of representation. It thus instates an approach which aims to "reveal as much about the culture and context of production as about the person whose life is examined" (ibid.: 316). Dementia is conceptualized here as a "narrative ploy" which enables particular messages about women, power and aging to be foregrounded (ibid.: 321). Deconstruction is not, however, fundamentally concerned with the authenticity of representations, or thus with their justice or injustice to particular social groups.

Leading ladies?

Aging, gender and power relations in dementia movies

We have touched earlier on the likelihood that interest in dementia within mainstream cinema will be motivated less by a desire to engage with social issues than by the potentially exciting things that can be done dramatically with the concept of memory loss. Greenberg notes that in its treatment of mental health issues, "mainstream cinema especially, if not always reliably, foregrounds *amnesia*, multiple personality disorder and other dissociative reactions because of their inherent melodramatic potential" (2003: 807 [emphasis added]). Baxendale (2004) argues that from the viewpoint of clinical neuropsychology, however, most mental health conditions in Hollywood films in fact bear little relation to reality. A report by Alzheimer Europe (2013) also highlights the inconsistencies of some filmic representations of memory in dementia more specifically.

All three of the general release feature films related to dementia recommended by cinemeducators that are discussed above – *Iris*, *The Notebook*, and *Away from Her* – have also been subjected to critique as representations from various theoretical perspectives that are not taken into account by the proponents of cinemeducation (see, e. g., Segers 2007; Chivers 2011; Gravagne 2013; Zeilig 2013). If, for example, we adopt a gendered

frame of reference for viewing these films, we find that each of them relates the story of the male spouse-carer of a female partner with dementia. This is already strikingly at odds with a social world in which the major proportion of care for people with dementia – both paid and unpaid – is provided by women. As Scheidt et al (2013) have also pointed out, even when the focus is ostensibly on the person with dementia as the central subject, the dominant perspective is that of the caregiver. In each case, moreover, the representation relates centrally to the male partner's loss, the burdens of caring for someone who is 'disappearing,' and the inexorable, progressive destruction of brain tissue.

In all three films, there is also a noticeable homogeneity of ethnicity, social class, and living arrangements; the three couples are white, married, heterosexual, and middle class or upwardly mobile professionals. In both *Iris* and *Away from her*, the central characters have met at university. This is unrepresentative of real-world social diversity among people with dementia and corresponds closely with Ludwin's definition of heteronormativity, that is,

[the] privileging of the individualised nuclear family over all other family arrangements: specifically the privileging of a particular, narrow form of heterosexuality, based on the married, monogamous, heterosexual, reproductive, nuclear family, which relies on (context specific) gender roles. (2011: 107)

It is unlikely that these tendencies in mainstream film will change significantly, but in contexts of both dementia research and education, those who wish to promote social inclusion and awareness of equality and diversity among people with dementia can promote the development of critical skills in reading film. In the final section of this chapter, we consider an alternative use of film that aimed to reduce the epistemic injustice described by Fricker.

TOWARDS EPISTEMIC JUSTICE

In 2006, Andrea Capstick was involved in a film-making project which led to the development of the short, independent arthouse film, *Ex Memoria* (Appignanesi 2006). Unusual at the time for its focus on the subjective experience of the central character with dementia, *Ex Memoria* was used for teaching Dementia Studies students for several years. Whilst the film consistently promoted discussion of the central character's troubled past and its impact on her present day experience of dementia (cp. Capstick 2007 for a full discussion), some commentators suggested that the performance of the

actor in the central role was not entirely convincing as a person with dementia. In keeping with the findings of Gerritsen (2014), in this case, the urge to avoid caricature or undue negativity resulted in a portrayal which for the most part resembled, as one viewer noted, “mild depression, rather than dementia.” As Miles and Plate (2004) note in their critique of capitalist/industrialist cinema, films made in these alternative traditions are more likely to encourage identification with the other as a fellow human being than as an alien or victim of disease. In the attempt however, they can lose credibility for those who encounter dementia in their own family or workplace. *Ex Memoria* was also filmed in a working care home, in the presence of real men and women with dementia, raising ethical questions about the exclusion of their own voices. The frequently cited slogan of service user involvement ‘Nothing about us without us’ seemed to apply here, and has led us over the intervening years to carry out a body of work (Capstick 2011; Capstick 2012; Chatwin and Capstick 2012; Ludwin and Capstick [in press]) in which people with dementia themselves appear in films made for educational purposes.

Bay Tree Voices is a participatory film-making project carried out in a voluntary sector day center in the Northern UK with ten people all of whom had moderate to severe dementia. The project was based on the principles of social inclusion and civic engagement which underpin both Participatory Video and Participatory Action Research (PAR) more generally. In PAR, the research process itself is change-oriented and the changes brought about are the result of collaborative social action between researchers and participants (McIntyre 2008). Unlike standard documentary, the film is co-produced with the participants and consists of a series of interactions, each just a few minutes long. The film was not scripted or rehearsed and, as a result, the interactions often have the character of ‘lucky finds,’ a term MacLure (2003: 173) uses to describe those momentary or unexpected events that can disrupt taken for granted ways of seeing.

The film we made with Cath, for example, acts as a corrective to the kind of mind-body dualism which results in a view of dementia as a ‘death that leaves the body behind.’

Fig. 1: Mind-body holism

Cath lived on a smallholding with her daughter, where for many years they had raised goats and sold milk. We first see Cath involved in a photo-elicitation exercise discussing pictures of goats. We then accompany her back home at the end of the day where she introduces us to her own goats, Daisy and Nimble, taking evident

pride in showing us around. In one particularly striking image, as we enter the stable where the goats live, Cath's hand goes out automatically to switch on the light, an example of what has been described as 'embodied (or procedural) memory' (Katz 2013).

We intentionally focused on people who were on the margins of the social life of the day center or with whom communication through usual channels presented some difficulties. As Chatwin (2013) has shown, micro-analysis of conversations with people with dementia is often the key to a new understanding of what they may be trying to communicate, and this was what we intended the film to demonstrate. A process of 'consent by editing' was used in which participants and their families saw the film before it was shown to anyone else and could indicate whether they wanted any changes or wished to have their image removed (cf. Capstick 2012). No changes were, in fact, requested, and the film is now used as the basis of a series of online discussions with students, relating, for example, to the often overlooked intersections between the lives of people with dementia and key events in social history (see Tom's story, below) and cultural practices of which many students were previously unaware (such as the use of prayer beads in Islam; see Shahida's story).

Fig. 2: Reinstating the person with dementia as 'knower'

Cyril spontaneously left a group game of Hangman taking place in the main lounge. We accompanied him on a walk along the corridor and into the reminiscence room. Cyril didn't show much interest in most of the objects in the room, including an old vacuum cleaner and iron, but his response to the 1940s radio set was sudden and enthusiastic; he picked it up and began to examine the back of the casing:

Cyril: The old radios, they used to work with a high tension battery and an accumulator, didn't they?

AC: (laughing) I'll take your word for it.... Do you know a lot about radios?

Cyril: Well, when I started work, I saved up and bought my grandfather one, and it worked with a high tension battery and an accumulator...

The historical and technical expertise Cyril displays here indicates that, on this particular subject at least, he is epistemically privileged; the expert on his own experience (Katz 2000).

Fig. 3: Recognizing citizenship

When we asked Brian if he would show us round the day center he seemed surprised at first, but readily agreed to do so. He told us he had been a keen gardener, and he was not entirely happy with the condition of the day center garden which he said he

would discuss with the manager (“It’s been neglected, which is a pity”). He describes a plant as “one little chap all on his own,” and explains that “from autumn through into winter we stop growing but they don’t.” Knowing about Brian’s former career as a transport policeman made sense of his tendency to become worried when the minibus delivering other people to the day center was late, and to wonder aloud about whether he should go and find them. Brian had also been closely involved in the Leeds Millennium Tapestry, images of which appear in the film with his voice-over commentary.

Here, Brian’s courtesy, concern for the well-being of others, and positive model of social citizenship contrast with the frequent portrayal of men with dementia as violent and aggressive in mainstream fiction films. His struggles to find the right word often resulted in a creative and philosophical turn of phrase.

Fig 4: Validating experience

Tom, an 89-year old man with dementia recounts in detail his experiences on fuel supply in the RAF during World War II. He makes precise and accurate reference to Hamburg, Arnhem, and El Alamein. He recounts movingly his reunion with his wife-to-be at the end of the war and the continuing reciprocity of their relationship: “When I go home today Betty will be waiting for me. We’ve been good to each other, Betty and me.”

Tom is well able to tell his own story from memory. As with most people with dementia, his recall for emotionally-charged remote events remains good.

Fig. 5: Learning from diversity

Shahida is South Asian and Muslim; she generally speaks only a few words in her first language. In the film, we see her unexpectedly take hold of a string of plastic beads during a small group activity and count them off, reciting something under her breath. Students were given the task of finding out about the use of prayer beads in Islam. Anton, a Romanian former refugee, is seen carrying a plastic bin liner along the corridor, scattering its contents on the ground and moving plant pots in the garden. Although little was known about Anton’s past, students were able to deduce from this that he had probably been an agricultural worker. His determination to continue carrying out a work role that was meaningful to him was very striking.

The contributors to *Bay Tree Voices* emerge as knowledgeable and often creative commentators. They also display significantly more social diversity in terms of their ethnicity, social class, economic status, and living arrangements than characters in the fictional sources discussed. It is interesting to note that of the ten people who took part in *Bay Tree Voices*, only

one belonged to a male caregiver-female care recipient dyad. Of the remainder, four were men living with female spouses and five were women whose daughter or daughter-in-law was the main caregiver.

In her conclusion to *Epistemic Injustice: Power and the Ethics of Knowing*, Fricker writes

In exploring epistemic injustice as an ethical phenomenon [...] this book also points to the possibility of a different sort of treatment, one more directly concerned with institutional conduct, and so placed more squarely in the political frame. (2007: 177)

As we were at pains to point out in the introduction to this chapter, the intention of this section has not been to contrast ‘bad’ films with ‘good’ ones, and nor is it to present a view of dementia that is more ‘truthful’ because based on real life encounters rather than fiction. Instead, it is to begin the work of actively ‘*doing* justice’ to people who have dementia through what Fricker describes as “epistemic affirmative action” (ibid.: 170).

CONCLUSION: SOCIAL PARTICIPATION AND EPISTEMIC JUSTICE

This chapter has argued that culturally-mediated epistemic injustice is a significant factor in the stigma which attaches to a dementia diagnosis. Fiction film is a popular vehicle for the perpetuation of negative and stereotypical views of people with dementia and one of the most influential ways in which fear and avoidance are reproduced. We hope to have demonstrated why such films, bringing with them the whole freight of the symbolic and representational order within which they are produced, cannot be used uncritically to raise awareness about dementia. We suggest that where mainstream feature films are used for educational purposes, this should be done in such a way that the view of people with dementia within them is problematized. Cinemeducation should make the process of learning more complex, rather than merely easier or more entertaining; it should ‘read against the grain’ (Jameson 1981) of mainstream representations.

A precondition for the epistemic injustice Fricker discusses is that those who experience it “participate unequally in the practices through which social meanings are generated” (2007: 6). We hope that the alternative body of data from *Bay Tree Voices* presented here has demonstrated that people with dementia are able to participate for themselves in the production of resources to be used for educational and consciousness-raising purposes. By foregrounding the diversity of people with dementia and their retained

knowledge and skills, we hope also to have indicated how it is possible to open up a different filmic discourse about dementia, one which is concerned with social justice and inclusion. Our own films are also representations. *Bay Tree Voices* is the edited end product of many hours' footage, and all film is inevitably 'reductive.' If we show the participants 'in a good light,' however, that is because it was part of the film's conscious intention to counter negative views and model successful communication. By amplifying real voices, we begin to counter the misleading tropes of global amnesia, irrational violence, and devastating erosion of identity which remain common in mainstream film.

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